

The Dedication: Leaving Evidence of Life, Death, Care, and Confinement During COVID-19

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Life: A Tapestry

ABSTRACT In 2020, the COVID-19 pandemic exploded and nursing homes rapidly became overwhelmed with disease, death, and despair. During this time, I learned Sylvia, an old woman with dementia I had befriended, was one of the many old and disabled people confined in nursing homes who did not survive. In this reflective and part personal, part scholarly essay, I leave evidence of and for Sylvia and the nearly 200,000 old and disabled people and care workers who contracted COVID-19 and died within the confines of neoliberal, profit-driven long-term care institutions. Disability justice activist Mia Mingus writes, "We must leave evidence. Evidence that we were here, that we existed, that we survived and loved and ached." Leaving evidence is a political act, a form of resistance in an ableist word. And yet leaving evidence is particularly challenging in the context of dementia, care, confinement, and death—making it even more important, more urgent. Building on Ellen Samuels' assertion, "Crip time is grief time," I consider how mourning Sylvia and countless other nursing home deaths, interwoven with my own experiences of distress, yet also solidified my need to survive, might leave evidence and keep working toward an abolitionist future—one in which old and disabled women like Sylvia, like my future self, might thrive.

KEYWORDS disability, time, care, COVID-19, aging, dementia

In late April of 2020, I wrote the last few words of my dissertation—the dedication: "To Sylvia . . . with whom this project begins and ends."

Sylvia (a pseudonym) is an old woman with dementia I came to care deeply for during my ethnographic research of a dementia unit in Cedarwood Care Center, a nursing home in the Chicagoland area, from 2018–19.¹ She was a kind, caring, affectionate person.

Yet, Sylvia was entirely secluded from the world outside of the nursing home. Her husband, Tom, had died nearly 20 years ago. Sylvia and Tom had three adult children, but they never

visited her.

The care workers whispered rumors that the children had abandoned Sylvia because, even before she developed dementia, she had “severe and persistent mental illness”. Like Sylvia, I have a long-term psychiatric disability. So, Sylvia and I connected, our crip, mad, demented bodyminds becoming deeply intertwined.²

As soon as I finished typing the dedication, I quickly searched Sylvia’s full name on the internet—a compulsive ritual I had developed ever since the pandemic exploded and nursing homes became overwhelmed with disease, despair, and death.

A result pops up. My heart sinks. It is exactly what I feared.

An obituary.

The tears make their way down my face, following familiar pathways. A deep ache forms in my heart. I wish I could have seen Sylvia just one last time. To tell her a final goodbye, to express how much she meant to me. But only “essential” personnel have been permitted in nursing homes for months now, leaving the old and disabled people confined in nursing homes more isolated than ever, as a feeble attempt to suppress the disease that was debilitating and killing the residents and the care workers at alarming rates. Sylvia was not the first old woman with dementia to die, alone, in a nursing home during the COVID-19 pandemic. And she would be far from the last.

In this reflective, part-personal, part-scholarly essay, I leave evidence of and for Sylvia and the over 200,000 old and disabled people and care workers who contracted COVID-19 and died within the confines of neoliberal, profit-driven long-term care institutions.

These narratives are idiosyncratic, nonlinear, and cyclical. They move between my time with Sylvia (2018–2019) and the unfolding of the COVID-19 pandemic. I mark the latter with dates but not the former. Much like Sylvia’s and my crip, mad, demented bodyminds, and much like my relationship with Sylvia, the vignettes are idiosyncratic. Nonlinear. Cyclical. Like grief, as my therapist likes to remind me, time and time again.

Building on feminist disability studies scholar Ellen Samuels’ assertion, “Crip time is grief time,” I consider how mourning Sylvia’s death and countless other nursing home deaths interweaved with my own experiences of distress, yet also solidified my need to survive, to flourish, to leave evidence.³

What follows is a story that evidences Sylvia’s life through the moments of its interaction with mine. It is a partial and fraught story, but the story of crip, mad, demented bodyminds

is often partial and fraught. Evidencing the complicated, relational, and contentious ways that our stories and lives overlap is essential to capturing crip pandemic life.

Leaving Evidence

What does it mean to leave evidence?

Disability justice activist Mia Mingus writes, "We must leave evidence. Evidence that we were here, that we existed, that we survived and loved and ached. Evidence of the wholeness we never felt and the immense sense of fullness we gave to each other."⁴

Leaving evidence is a political act, a form of resistance in an ableist world. Historically, disabled people have been excluded from leaving evidence. The very structure of society renders disability and disabled people invisible and unknowable. We are hidden, segregated, and locked away in our family's homes, special education classrooms, sheltered workshops, nursing homes, psychiatric wards, hospitals, jails, and prisons. We have been subject to exploitation, impoverishment, violence, war, environmental catastrophes, and a neoliberal capitalist political economy—"all of which produce, propagate, and proliferate disability while simultaneously rendering disabled people completely invisible."⁵ Often surviving in isolation, we have had to fight to find one another. As Leah Lakshmi Piepzna-Samarasinha notes, "Ableism isolates and keeps disabled, Deaf, neurodivergent people from finding disabled, Deaf, and neurodivergent communities."⁶ This struggle to find one another, to connect across space and time, to celebrate our interdependence is why leaving evidence is so important.

And yet leaving evidence is particularly challenging in the context of dementia, care, confinement, and death. How do we leave evidence for those who are confined? How do we leave evidence for those without any access to the outside world? How do we leave evidence for those who have not survived?

My research at Cedarwood Care Center raises a lot of questions about whether I have a right to tell the stories of Sylvia and other old women with dementia. How do you tell a story like theirs, a story that deserves to be told without "using" Sylvia, her works, her mind, and her body? These are important questions but ones that can only be grappled with alongside the following question: what are the risks of *not* telling their stories?

Disabled and old people are seen as separate, individual, and disconnected from both each other and non-disabled people. These ideas can intensify the ethical questions about speaking for others by creating a sense of heightened vulnerability and obscuring the connections that link their stories and experiences to others. As Alison Kafer observes,

disability is relational; it is “experienced in and through relationships” and “does not occur in isolation.”⁷ As disabled people, we are keenly aware of our interconnectedness, or what Margaret Schildrick and Alyson Patsavas have referred to as “leaky bodies”—in which disability is an “experience that flows through, across, and between always-already connected bodies.”⁸ It is this relationality that I track here. It is this relationality that I hold center as I prioritize questions of assent and presumptions of intentionality with folks deemed “incapable” of either. It is this relationality that shapes my efforts to speak with rather than for.

The deep bond I shared with Sylvia reflects the leakiness of our bodyminds, the ways our joy and our pain and our longing for freedom often melded in a place dominated by carceral, neoliberal, capitalist logics. I cannot leave evidence of my own experience or of Sylvia’s experience, I can only leave evidence of *our* experiences—our togetherness, our intimacy, our shared anguish, hopes, and dreams.

Seeking Connection

I initially encounter Sylvia from afar. It is my first day at Cedarwood Care Center, and the Head Nurse of the Alzheimer’s and Special Care Unit is giving me a tour. Sylvia walks around the dementia unit. The Head Nurse describes her as “wandering” and “unaware.” However, as I observe Sylvia, calmly walking in a purple sweatshirt with a long, beautiful, gray braid, I do not agree with the Head Nurse. Sylvia rubs a cloth hamper in the common area for a minute. She then takes a cup that had been left nearby and holds it against the hamper, as if filling the cup at a water cooler. She rubs the cup up and down the hamper several times and then laughs. “I think we are all out!” She then sets the cup down and walked away. Ableism and ageism precondition a reading of Sylvia’s actions as unintentional, evidence of nothing more than her diagnosis. I understand her action as more purposeful than the Head Nurse believed—I witness someone seeking touch and sound and feedback, trying to meet her needs in a place of deprivation, isolation, and confinement. I feel a connection I cannot yet quite explain.

The Start of the Pandemic

February 29, 2020.

The first confirmed outbreak in the United States is in a nursing home in suburban Seattle, Washington.⁹ I knew it would be.

I reach out to the care workers I developed relationships with at Cedarwood Care Center. "Be careful. Be safe," I beg them. They promise they are being as careful and as safe as they can. "Let me know what I can do," I add. We all knew there was nothing any of us could do, really. That it was only a matter of time.

Free Me, Otter, Otter, Daughter

The next time I come across Sylvia, she is sitting in the lobby, on the sofa facing the aquarium. I attempt to approach her, but a religious leader and doctor walk up before I could.

Doctor: Do you have any pain? Are you tired?

Sylvia: No.

Doctor: You are doing great today!

Rabbi: You have a beautiful daughter. Is she beautiful like you?

(Sylvia blushes and appears pleased but also embarrassed.)

Doctor: What did you have for breakfast?

(Sylvia does not answer.)

Doctor: What religion are you? Do you know who this (gestures to rabbi) is?

(Sylvia does not answer.)

Doctor: You are Jewish!

(Sylvia smiles but still does not respond.)

The doctor and the rabbi walk away, the doctor writing in his notes. I am struck by how much that "conversation" with Sylvia is just between the doctor and the rabbi. I think about the many times I have felt unheard by psychiatrists and therapists, about the ways that, as disabled people, we are often overlooked, ignored, or misunderstood by doctors and others who have power over us.

A few days later, I am finally able to speak with Sylvia for the first time. She is once again sitting on the sofa, in the lobby, but this time by herself. Her elegant long, silver hair is swept up in a bun, and as I approach I notice she is sitting next to a baby doll.

"Hello, Sylvia, my name is Hailee. I am spending time here, at Cedarwood Care Center, to learn more about what it is like. Can I talk to you?"

Sylvia smiled up at me. "Yes!"¹⁰ Additionally, the participants with dementia in this study provided verbal and non-verbal assent. Assent refers to an affirmative agreement to engage with the researcher and participate in research. Assent is used to ensure the ethical participation of people who are not legally permitted to provide informed consent.

Assent was obtained from the individual with dementia at the start of the conversation or interview. I also checked in with the participants at various points to ensure they were still comfortable answering questions or talking. If the resident was restless, agitated, having sudden mood changes, or seemingly disengaged, I recognized this as a revocation of assent and ended the interview or interaction.] I sit down next to her. She then begins talking. "They put me in here. Free me. Otter. Otter. Daughter. Please."

Understanding that Sylvia is asking for freedom, my heart breaks a little. I think about how being institutionalized in a psychiatric ward has always been one of my greatest fears. I think about the many marginalized people in US society denied the basic rights of freedom. I reflect on all the masking, performing, and hiding I have needed to do to avoid being confined—something Sylvia, as an old single woman with dementia, was unable to do. I feel the walls of the dementia unit closing in on me. I see them closed around Sylvia. "I wish I could free you," I tell her, quietly, meekly, feeling helpless and hopeless.

Sylvia pats my hand, comforting me. She then gestures to the baby doll. Almost as if knowing that I needed to talk about something else. "Oh, is that your baby?" I ask. "Yes!" Sylvia responds, once again smiling. "How cute!" I tell her. "What is your baby's name?" I ask. "Sylvia responds, "Freddie Joy Fader. Until someone brings us. Come home. And they'll go away. She has to go, until I go. It was twenty. Twenty." I nod in agreement. "I hope they bring you and Freddie home," I say softly. Sylvia responds, "It's probably more morning. This is the thing that has to be earned. Can I do that without the trip? Is a seagull coming?"

The Epicenter of the Pandemic

I quickly become fixated on, perhaps even obsessed with, the death toll in nursing homes.

March 7, 2020.

The nursing home in suburban Seattle, described as the "epicenter" of the outbreak, reports thirteen residents have died from complications related to COVID-19.

Approximately seventy care workers are sick.¹¹

March 14, 2020.

"Trump Administration is Relaxing Oversight of Nursing Homes."¹² The *New York Times* headline, in stark black lettering, overwhelms me. The Trump administration has been pursuing this loosening of regulations, which includes relaxing rules intended to prevent and lessen the spread of infectious disease, since July 2019. I wish I felt surprised it was still being pursued as COVID-19 rapidly spreads. But the Trump administration has never cared about marginalized people's lives. And old and disabled people in nursing homes are out of sight, out of mind. "We have to make sure that our regulations are not so burdensome that they hurt the industry," Seema Verma, an administrator for the Centers for Medicare & Medicaid Services claims. Because a multi-billion-dollar industry must be protected at all costs—even if the cost is old and disabled people's lives. I already know the impact will be worse in for-profit nursing homes, which comprise 70 percent of all nursing homes and are more likely to confine poor Black, Indigenous, and People of Color (BIPOC). Helpless, hopeless, I wait for the number of sick and dying people in nursing homes to surge.

March 21, 2020.

As expected, the death toll continues to climb, slowly but surely. Approximately seventy-three nursing homes and other congregate care facilities in twenty-two states now report cases of COVID-19.¹³ The article describes the virus as "the almost perfect killing machine." Now, fifty-five disabled elders have died—one-quarter of all deaths.

Bed, Sun, Horse

When Sylvia has a cognitive evaluation, administered by one of Cedarwood Care Center's social workers, she "failed."¹⁴ She is unable to answer a single question about where she currently lives, what city she is in, what three words the social worker had asked her to remember and regurgitate.¹⁵

Bed. Sun. Horse.

The social worker simply says, "Okay, thanks Sylvia," before proclaiming Sylvia is "gone" and "just kind of stares at you."

Gone. "Alive" yet . . . dead.

All because she can not repeat:

Bed. Sun. Horse.

The social worker asks all the wrong questions, I think. These are questions built on an ableist notion that ties personhood and presence to memory. Sylvia has dementia, in addition to other mental and communication disabilities. Of course, she is unable to answer these types of questions in a way that “made sense” to the social worker.

But Sylvia often makes sense to me.

Is A Seagull Coming?

“Is a seagull coming?” Sylvia’s question after our first interaction echoes in my mind for days. I neatly write it down in my field notes.

This question may seem meaningless—a jumble of words with no significance. Medically, it would be understood as a sign of aphasia, or the loss of the ability to understand or express speech. It would be pointed to as a sign that Sylvia’s dementia was progressing.

Feminist disability studies scholar Margaret Price argues, “The failure to make sense, as measured against and by those with ‘normal’ minds, means a loss of personhood.” These dismissive views deny people like Sylvia rhetoricity, or the ability to be received as a “valid human subject.”¹⁶ As Price explains, rhetoricity refers to the ability to be understood and for one’s communication to be heeded and valued. People with dementia are primarily denied rhetoricity because of bodymind experiences associated with dementia, such as memory loss, disorientation, or aphasia. Consequently, they may not “make sense” to those around them according to dominant “rules” of communication.¹⁷

Leaning on Price’s assertion, I understand Sylvia’s question was asked in the context of what I have termed “dementia time,” a temporal dis/orientation disrupts normative time.¹⁸ In dementia time, individual moments may be self-contained, nonlinear, intermittent, irrational, and idiosyncratic—yet they are no less meaningful or valuable. Rather than demanding that people present linear, coherent, rational narratives, dementia time asks us to consider how a person “makes sense” in that specific moment and context. It invites us to exist together in a world that values authorship, listening, creativity, imagination and flexibility over rigid, linear, logical, rational forms of communication and connection. We may think, communicate, understand, and move through the world differently from one another yet we still exist—together and connected—in this queercrip time and space.

So, if we value Sylvia’s question, if we recognize it as meaningful and engage with it as such: why might have Sylvia inquired whether a seagull is coming after asking to be freed from the confines of the nursing home?¹⁹ Disability studies scholar and rhetorician Elisabeth Miller examined the communication practices of people with aphasia (who did not

have dementia) and found that this form of invention, which relies on close listening, context clues, gestures, and images, was used to cocreate meaning as a form of communicative access. [Elizabeth Miller, "Negotiating Communicative Access in Practice: A Study of a Memoir Group for People with Apraxia," *Written Communication*, 36, no. 2, 197-230.] While I could not ask Sylvia to explain her use of the word seagull in a way that I could fully understand, I cocreated meaning with her by considering the words she used (free me, freedie), how often she used them, where she had chosen to sit (near the exit), and other signifiers. This process allowed me to respect Sylvia's authorship and rhetoricity by understanding her question as purposeful and important.] What does a seagull symbolize?

I spend an afternoon reading about seagulls, their lives, and how their presence has been interpreted by others, naturally, culturally, and spiritually.

I consider what a seagull symbolizes.

Ultimately, I write in my notes, "Freedom. Collectivity. Flourishing. Life." I skip a line and continue, "Messengers of changing tides and changing times."

Alive . . . Yet Dead

Sylvia was viewed as adjacent to death, as in the process of dying, for years. Long before the pandemic. Long before her actual death.

What is death? What does it truly mean to die?

In dominant US culture, people often avoid this question, hiding and shielding themselves from any conversation focused on their vulnerability or waning vitality. They cling tightly to their youthfulness, able-mindedness, and able-bodiedness.

Those marginalized by age, disability, race, gender, class, immigration status, and sexuality often understand that death is always possible, always close in a world that does not value us. And the pandemic made it even harder to circumvent death. Death is constant and unrelenting.

Legally and medically, death is defined as, "irreversible cessation of cardiorespiratory function or irreversible cessation of all brain function."²⁰ Western culture generally accepts this view—but with a particular focus on "brain death" as a marker of loss of life, given the broad acceptance of mind-body dualism and the ideas that consciousness, thought, and "the self" are key aspects of life that reside in the brain. But if we understand death as the

ending of brain function, what does that mean for old people with dementia, who are constructed as “losing” their minds?

Bed. Sun. Horse.

Gone. “Alive” yet . . . dead.

Colloquial healthcare discourse describes dementia as a “brain robbing” or “brain rotting” illness.²¹ Consequently, within popular culture, people use metaphors for dementia such as “the long goodbye” and “the everlasting funeral.”²² Medical experts and social workers often tell caregivers to expect “anticipatory grief,” which refers to grieving the death or loss of the person with dementia before their actual deaths.²³ These medical and cultural references and practices reflect the belief that those with dementia, as they increasingly struggle to meet the norms of memory, communication, orientation, and rationality, are “lost,” “gone,” or even “dead” long before meeting the legal and medical definitions of death. Susan Behuniak notes that the metaphor of old people with dementia as “the living dead” is pervasive and a key aspect of dehumanization.²⁴

Thus, it is endemic in US culture to view old people with dementia as constantly dying or already dead—as people who are slipping away, becoming shells of their former selves. Scientists and medical experts have labeled COVID-19 as endemic too, and this construction of old people with dementia creates a cultural belief that their deaths—COVID-19 related or not—are inevitable, tolerable, perhaps even merciful.

Are we becoming too comfortable, too desensitized to death? Or is it that the deaths of “the living dead,” those who are old, disabled, “demented,” do not matter?

Time to Care

April 17, 2020.

At least 7,000 dead. “They’re death pits,” I read in a *New York Times* article.²⁵ Haven’t they always been? Nursing homes—where old disabled people go to die. Maybe that’s why no one cares.

I feel isolated, afraid, distressed. I sleep late. I cry about Sylvia. I cry about the many other old people with dementia I befriended. Alice. Margaret. Lucille. Fauna. Bernard. Isabelle. Sophea. Betty. Bernice. Herbert. Ramona. Tala. Eleanor. Marlene. Harry.²⁶ I cry about all those who are dying in nursing homes, prisons, immigration detention centers.

I cannot bring myself to search for the others’ names. I cannot handle all this death.

Time warps. Each day feels like a decade, yet the days simultaneously pass quickly.

I continue to keep close watch of the death toll in nursing homes. Depending on the day, context, and news outlet, nursing home deaths account for 25–70 percent of all deaths.²⁷ The numbers typically include both old and disabled people and care workers, many of whom are marginalized by race, gender, class, and immigration status. Outbreaks in spaces of confinement adjacent to nursing homes, such as jails, prisons, and immigration detention centers, which predominantly incarcerate poor, disabled, BIPOC also increase rapidly.

Still, nothing is done. These are the people our society has disregarded, locked up, thrown away, dehumanized.

I dream about a disability justice, abolitionist approach to care, about eradicating institutionalization, about freedom, collectivity, flourishing, life. Is a seagull coming?

Our Disabled Elders and Ancestors

For disabled people, elderhood is often elusive. Many of us do not make it to elderhood. It is assumed that we do not survive because of our illnesses and impairments, our weakened immune systems, or progressive disabilities. At times, that is true. But many of us also die due to racist, ableist, and ageist structures such as medical neglect, for-profit healthcare, violence, and institutionalization. Some of us die from overdoses and self-medicating and suicide. Disabled people die in “systems that don’t see their lives as worth living and fighting for.”²⁸ Consequently, being an elder in crip, disabled, mad communities, particularly queer, trans, and BIPOC communities, is rare.

As Leah Lakshmi Piepzna-Samarasinha posits in a conversation with Stacey Milbern, “I both do and do not have disabled QTBIPOC elders in my life. Ancestors, yes. Elders not as much. Elderhood is not a state that just happens. Disabled QTBIPOC elderhood is dependent on systems that support it being there.”²⁹

Our current neoliberal, capitalist structures of care do not support elderhood for millions of old and disabled people, especially those with dementia.³⁰ Nursing homes isolate, exploit, and dehumanize. They extract value from old and disabled people and care workers, resulting in huge profits for the nursing home industry. These spaces of confinement, which purport to care for people, are yet another form of state-sponsored violence and death.

As a community, when we examine our disability or crip lineages, when we look to and for those who came before us, we come to understand that many of our elders have become

ancestors. Stacey Milbern explains, "People sometimes assume ancestorship is reserved for those of biological relation, but a queered or crippled understanding of ancestorship holds that . . . our deepest relationships are with the people we choose to be connected to and honor day after day. Ancestorship, like love, is expansive."³¹ Crip ancestorship is a way of holding on to those who came before us. We continue to learn from and create knowledge with our ancestors, demand change building on the work of our ancestors, and fantasize about the radically different world we could create, the world our ancestors want for us.

As feminist disability studies scholar Akemi Nishida notes, we must dream and imagine radical futures in which care is outside of state control, surveillance, and violence, and is instead a site of connection, a messy yet collective process, a marker of our interdependence.³²

As we dream and imagine, we need to ensure that old and disabled people in spaces of confinement are included in these futures.

Once when I was sitting with Sylvia in a common area of Cedarwood Care Center, she suddenly stood and announced, "I want to go." "I know, I'm sorry," I say. "That's all I have," she replies. "I know." She continues, "Maybe I shouldn't say anything but if you had some good things, things good. I only have some good trades, makes, grades. Let's go! Just let me go. Because I got to go. I just have to get out. To that." She points to the window, to the blue sky and the shining sun.

Institutionalized old disabled people—many of whom are negatively gendered, racialized, and classed—are our elders. They are dreaming of a different world for themselves, for us. But they are also dying. And they are holding these dreams for us as they transition to the ancestral plane. As Stacey Milbern reflected, "My ancestors are disabled people who lived looking out of institution windows wanting so much more for themselves."³³

Sylvia was once my disabled elder. Now she is my ancestor. This transition marks the continuation and expansion of our story, not the end.

As queer feminist author and disability studies scholar Jennifer Natalya Fink claims, "Our disability lineages can only be reclaimed through the stories we uncover."³⁴ This is why we must leave evidence.

Time to Grieve

Because of the pandemic, Sylvia's graveside service is private. I hold my own, personal memorial in my bedroom. I light a candle, and I listen to a recording I took on the very last

day of my research—a recording I have not listened to since then.

The recording is evidence of my goodbye to Sylvia. I still cannot articulate exactly why I decided to record it. I think it was because I lost my dad in the middle of my fieldwork. My dad had been placed in hospice before he died, which had provided me with time to reflect on our complicated relationship and think about how I wanted to say goodbye to him. After his death, I continued to think about goodbyes—what they mean and how often in our society we deflect and avoid them. So, when it is time to say goodbye to Sylvia at the end of my fieldwork, I approach it intentionally and want it memorialized in some way—as a special and significant moment in time.

While writing this piece, I fulfilled a promise I had made, to myself, to Sylvia a long time ago. A promise I previously could not bring myself to honor. I needed time.

“Crip time is grief time,” Samuels writes.

I visit Sylvia’s grave. I play the recording for her, and I weep.

Hailee: Sylvia, I’m going to miss you.

Sylvia: Yes.

Hailee: I’m going to miss you a lot.

Sylvia: Oh, me too!

Hailee: I love you.

Sylvia: I do too. [A huge smile spreads over Sylvia’s face.]

Hailee: I like your big smile.

[Sylvia laughs and presents her cheek for me to kiss, and I oblige.]

Sylvia: That’s good, that’s one. I was glad!

The Dedication

To Sylvia . . . with whom this project begins and ends.

“We must leave evidence.” Mia Mingus’ words reverberate through my bodymind.³⁵

As an ethnographer, my time in the nursing home was intended to be centered on “collecting” evidence, not “leaving” evidence. Collecting is about gathering, about taking. It

reflects the colonial, white supremacist, and ableist roots of research. Leaving is about giving, rejecting invisibility and disposability, elevating our stories. Reflecting on Mingus' call to leave evidence, Adriana van Altvorst asserts, "Our stories of survival expose us and unite us."³⁶

As an old woman with dementia, confined in an institution during a pandemic, Sylvia was meant to not survive. As the care workers once told me, "For most people, death is the only way to leave this place."

But the stories of Sylvia and the hundreds of thousands of old disabled people who died in nursing homes—many of whom were further marginalized by gender, race, and class—survive through us. As Alice Wong observes, "[Our stories are] something that we're going to pass on to other people when we're nothing but dust."³⁷ Those who have died in nursing homes since the onslaught of the COVID-19 pandemic were once our disabled elders. Now they are our ancestors.

Sylvia talked and laughed often. She walked the entire unit and would sometimes find objects that seemed to create pleasant surprises, like an uneaten cookie left on a tray or a hairbrush on a couch. She sang enthusiastically, especially the song "My Bonnie." She was physically affectionate, holding hands and hugging others. I frequently witnessed her comforting those around her when they appeared distressed. She complemented those around her, often telling the care workers and other people with dementia in the nursing home that they were beautiful and wonderful. She was very fashionable. She often experienced her husband, Tom, as being in the room with her—announcing, "Tom's right there!" while smiling and laughing. Sylvia would sometimes ask to look at my "book" (my field notes). She would flip through the notebook and make encouraging comments like, "Fabulous!" or "How precious!" She spoke, moved, and communicated in ways that made it clear how much she longed to be free, to go home. This is how Sylvia lived.

This is why we must leave evidence.

Changing Times and Changing Tides

As of February 2022, the Centers for Disease Control reported that more than 201,000 old and disabled people and care workers in nursing homes and other long-term care facilities have died since the beginning of the pandemic.³⁸ That number continues to climb, with tens to hundreds of nursing home residents continuing to die of COVID-19 each week, especially during cold weather peaks.³⁹Footnote: The statistic of 201,000 COVID-19 related deaths of long-term care residents and care workers is likely a significant undercount due to a number of factors. First, resident and care worker deaths were not

tracked prior to June 2020. Second, state reporting was inconsistent and some states did not report deaths for long-term care facilities other than nursing homes (e.g., assisted living facilities, group homes). Third, long-term care facilities other than nursing homes were not tracked after June 30, 2021. These issues have prevented the Kaiser Family Foundation and similar entities from providing updated data that includes all residential long-term care facilities. The most up to date data is only inclusive of nursing homes. The AARP reports resident and care worker deaths in nursing homes at 180,000 as of May 2023. As noted by the AARP, inconsistent data tracking throughout the pandemic has hindered efforts to fully understand the crisis in long-term care facilities and to address it.

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201,000. This is 16 percent, or 1 in 6, of all COVID-related deaths in the U.S.

For so long, many of us have just been trying to survive. Many of us in institutions, like Sylvia, did not.

This is why we must leave evidence.

Is a seagull coming?

I am dreaming of an abolitionist future. A future defined by freedom, collectivity, flourishing, and life. A future in which multiply-marginalized disabled and old people might not only survive but thrive.

I am leaving evidence. And I am dreaming of changing times and changing tides—of a different world. For those still confined. For my future self. For us.

Notes

1. All names of people and places are pseudonyms. ↩
2. I acknowledge that “demented” is a loaded term and readers may pause at it. The majority of people with dementia have rejected it. Yet, I use “demented” here as a political category, similar to crip, mad, and queer. These are reappropriated and reclaimed terms to signal empowerment, politicization, and interconnectedness, even as many disabled, psychiatrically diagnosed, and LGBTQIA+ folks, respectively, may not use such terms. I am interested in exploring demented as a radical coalitional term that more directly and broadly applies to people with diverse mental disabilities. Demented, as a label, refers to people socially constructed as “crazy,” mad, behaving wildly or irrationally.” Demented more clearly fits into crip politics, rejects diagnostic language (which is an important project of feminist disability studies), and attempts to reclaim a term that has been used to dehumanize those of us labeled as “out of our minds.” As Floyd Skloot, a writer and activist with dementia who seeks to challenge the way we understand what it means to be “demented,” noted: “When demented breaks down into ‘de’ for ‘out of’ and ‘ment’ for mind—literally ‘out of my mind’—I interpret the verbal construction as having positive connotations. Not looney, but liberated. Forced out of my mind, forced away from my customary cerebral mode of encounter, I find myself dwelling in wilder realms of sense and emotion” {Floyd Skloot, *In the Shadow of Memory* (Lincoln, NE: University of Nebraska Press 2003), 21–22}. I am not using demented to describe Sylvia but rather applying the term to describe Sylvia and my bodymind connections and relationality. ↩

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6. Leah Lakshmi Piepzna-Samarasinha, *The Future is Disabled* (Vancouver: Arsenal Pulp Press, 2022) 24. ↵
7. Alison Kafer, *Feminist Queer Crip* (Bloomington, IN: Indiana University Press, 2013), 8. ↵
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9. Mike Baker, Nicholas Bogel-Burroughs, and Karen Weise, "Washington State Declares Emergency Amid Coronavirus Death and Illnesses at Nursing Home," *New York Times*, February 29, 2020, <https://www.nytimes.com/2020/02/29/us/coronavirus-washington-death.html> <
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10. I engaged in multiple strategies to ensure this research project was ethical. The research was approved by the University of Illinois at Chicago Institutional Review Board and by the Cedarwood Care Center administration. Written consent for the participants with dementia was obtained through each individual's Legally Authorized Representative. Murphy et al. emphasized that legal proxies should be used to include (rather than exclude) people with advanced dementia in research. [Kathy Murphy, Jordan Fionnuala, Andrew Hunter, Adeline Cooney, and Dympna Casey, "Articulating the Strategies for Maximising the Inclusion of People with Dementia in Qualitative Research Studies," *Dementia*, 14, no. 6 (2015): 800-824. ↵
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<https://www.nytimes.com/2020/03/14/business/trump-administration-nursing-homes.html> <
<https://www.nytimes.com/2020/03/14/business/trump-administration-nursing-homes.html>> . ↵
13. Peter Whoriskey, Maria Sacchetti, and Richard A. Webster, "Coronavirus Cases Surge at Nursing Homes as Workers Battle 'Almost Perfect Killing Machine,'" *New York Times*, March 21, 2020.
<https://www.washingtonpost.com/business/2020/03/21/nursing-home-coronavirus-deaths/> <
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14. This evaluation was done in a common area of Cedarwood Care Center, as I was sitting next to Sylvia. I was given assent by Sylvia to continue sitting with her during the evaluation and I was given assent by the social worker to observe and record the evaluation for the purposes of my research. ↵
15. To be clear, I do not agree with the social worker's assessment that Sylvia "failed." Rather, I am critiquing the premise and structure of the test and how it actually creates conditions for failure because it is based on dominant, ableist norms of thinking and communication. ↵
16. Margaret Price. *Mad at School* (Ann Arbor, MI: University of Michigan Press, 2011), 26–27. ↵
17. Hailee Yoshizaki-Gibbons, "Time and Aging: Old Women and Care Workers Navigating Time, Relationality, and Power in Dementia Units," PhD diss. (University of Illinois at Chicago, 2020). ↵
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 26. As previously mentioned, all names are pseudonyms to protect participants' privacy and confidentiality. ↵
 27. Articles often focused on different locales, states, or regions. Some focused on the United States on a national level. See Dylan Matthews, "America's COVID-19 Hot Spots Shed a Light on Our Moral Failures," *Vox*, May 1, 2020, <https://www.vox.com/future-perfect/2020/5/1/21239396/covid-19-meatpacking-prison-jail-moral> < <https://www.vox.com/future-perfect/2020/5/1/21239396/covid-19-meatpacking-prison-jail-moral>> ; Elaine Godfrey, "'We're Literally Killing Elders Now,'" *The Atlantic*, April 29, 2020, <https://www.theatlantic.com/politics/archive/2020/04/coronavirus-especially-deadly-nursing-homes/610855/> < <https://www.theatlantic.com/politics/archive/2020/04/coronavirus-especially-deadly-nursing-homes/610855/>> . ↵
 28. Leah Lakshmi Piepzana-Samarasinha, *The Future is Disabled* (Vancouver: Arsenal Pulp Press, 2022), 137. ↵
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